

Creative Methodologies to Enhance Communication

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Accessible Summary

- Those who support people with learning disabilities should listen carefully to what they have to say.
- Whilst sharing life stories can be a good way to listen to someone, not everyone is able to talk about their story.
- Here four people who have a learning disability share their stories by singing, taking photographs or making a scrap book, and looking for themes in their work.
- The four people enjoyed their work and found that sharing it with others was a helpful way to let people know something about their lives, their skills, and what is important to them.

Summary

The experiences and opinions of people with learning disabilities are often ignored or devalued. Oral and life history projects allow individuals to communicate their own opinions and experiences. This process can lead to more meaningful interactions between those with learning disabilities and support workers. Whilst the interview techniques often employed by life history projects may not be appropriate for those with limited verbal abilities, alternative methodologies such as photography, drawings, music and poetry may be adopted. The current study demonstrates that a life history approach incorporating creative techniques can provide valuable information about the beliefs, experiences and values of people with learning disabilities. Therefore, creative forms of communication should be encouraged in order to promote personalised care and greater representation in learning disability research.

Keywords: Communication; Creativity; Inclusion; Life History; Participation

Introduction

Learning disabilities affect a large and increasing proportion of the British population (Emerson and Hatton, 2008). These disabilities are often associated with impaired communication (Aram and Nation, 1975). As a consequence, the experiences and opinions of men and women with learning disabilities are often ignored or devalued (Klotz, 2004). Restricted communication may increase the frustration experienced by those with learning disabilities and encourage dependence on others. This is of particular importance as power is an important feature of relationships with carers and infrequent or poor quality interactions may further disempower those with learning disabilities (Finlay, Walton and Antaki, 2008). This reflects common definitions of learning disabilities which focus on reduced abilities to understand information and a reduced ability to cope independently (Valuing People, 2001, 2005, 2009). This type of deficit definition serves to facilitate the removal of power from those with learning disabilities and hinder a more complex appreciation of the abilities that men and women with learning disabilities possess (Bogdan and Taylor, 1982).

Communication difficulties also increase dependence on family members (O'Shea, 2009). For example, professional carers frequently rely on information and interpretation provided by relatives. The assumption that relatives intend to (and are able to) accurately convey the wishes of those with communication difficulties is problematic. For example, relatives may not be available and there is a risk of abuse. Thus many people with a learning disability are reliant on support workers (Emerson and Hatton, 2008). Though a number of communication aids are available (see Gevarter et al. 2013 for a review), such as the use of picture exchange communication systems, these are often intended for simple interactions only such as a request for food. Whilst beneficial, these do not necessarily allow those with communication difficulties to convey their beliefs, values and emotions and for carers to understand what individuals need in order to make their lives meaningful (Hamilton and Atkinson, 2009). In part this may reflect a general neglect of this subject area (Adams and Oliver, 2011).

Knowledge of an individual is essential for the selection and delivery of appropriate care. Oral and life history projects which allow individuals to communicate their own opinions and experiences, have been conducted with a range of marginalised groups, including those with learning disabilities (Atkinson, 2004; O'Shea, 2009). In particular, a life history project conducted by The National Institute for Intellectual Disability (NIID,) documented the key events and experiences of adults with learning disabilities. The material was obtained organically (i.e. without interviews schedules), allowing men and women with

learning disabilities to focus on the subjects that they regarded as important (Hamilton and Atkinson, 2009; Hughes and Brennan, 2010). This approach can empower those that are often marginalised and lead to more meaningful interactions between support workers and those with learning disabilities. Whilst the interview techniques often employed by life history projects may not be appropriate for those with limited verbal abilities, alternative methodologies such as pictures, photography, drawings, music and poetry may be adopted (Lykes, 2000; O'Shea, 2009). Indeed this form of creative process may have other benefits for those with learning disabilities such as promotion of health and wellbeing (Batt-Rawden, 2010), reduction of self-injury (Savarimuthu and Bunnell, 2002) and identifying otherwise hidden talents (Sulaiman and Bajunid, 2012).

The current study aims to demonstrate that a life history approach incorporating creative techniques can enhance communication between support workers and those with learning disabilities. In particular, it is proposed that these techniques provide valuable information about the values and priorities of an individual such as the techniques used to cope with distressing events and can therefore inform future care and support based decisions. Addressing the disempowerment often experienced by men and women with learning disabilities, the study adopts an inclusive, collaborative and participatory approach.

Method

Much thought was given to a design and methodology that would include the men and women involved as much as possible. The study was therefore based on the Life History research project conducted by the National Institute for Intellectual Disability (NIID) at Trinity College, Dublin (Hamilton and Atkinson, 2009; Hughes and Brennan, 2010), in which the subject matter was guided by participants. The author has long-term relationships (not based on employment) with the four adults invited to take part in the study and an inclusive and participatory approach was adopted from the outset. The design of each session was collaborative and the choice of creative media used was entirely controlled by individual participants, their particular strengths and preferred way of working. Analysis was carried out together as much as possible, and the author consulted with each participant over any thematic analysis conducted. All four participants were members of a Lancashire (UK) residential community which offers 24 hour care to adults labelled with a learning disability. Each individual requires substantial support with daily living and personal care. Verbal communication differs across the sample.

As the medium adopted by each participant (music, photography or collage) was guided by individual interests, preferences and method of relating to the world, the creative

techniques employed by each individual varied and are outlined separately below. A research question was not imposed on those involved as the purpose was to provide a space and the means for each individual to communicate about their life, by focusing on their skills and interests and combining these with life story methodology. Formal ethical approval was obtained from the University Ethics Committee and phased consent was obtained at three separate stages. This aided the participants' understanding at each stage of the study and attempted to address some of the power imbalances involved. Consent included choosing to: a) work with the researcher to produce a piece of work about their life; b) discuss themes arising from the work with the researcher and; c) include the themes in a final report. At the end of the study each person had produced a piece of work (e.g. CD) which was theirs to store or share as they wished.

Charles and Anne

Charles and Anne enjoy making music, particularly improvisation. Four sessions were spent recording Charles singing and then listening to the recordings together. Two sessions were spent recording and listening to Anne's songs. Each session lasted approximately 90 minutes and no prompts were used. Whilst listening to the songs with Charles or Anne, the researcher made notes about themes and a reflective account was written after each session. All songs were transcribed, coded and subject to inductive thematic analysis at the latent level. All themes from this analysis were discussed with Charles and Anne for agreement.

Becky

Becky is constantly attentive to a carrier bag which contains a variety of paper such as raffle tickets, envelopes or flyers. Becky was provided with different types (i.e. colours, sizes and textures) of paper, together with magazines, scissors, glue, pens and shaped punches. There were also folders, envelopes and a scrap book. Work evolved over six sessions of 90 minutes, guided by Becky's preferences. Comments made by Becky during the process were recorded next to the relevant picture/paper and occasionally the author asked why a particular picture or paper had been chosen. Themes from the scrap book developed during the sessions were discussed and a reflective account was written after each session. The author coded the pictures and text and constructed themes from the work which were discussed with Becky for agreement before being included in the report.

Nick

Nick enjoys taking photographs. Two sessions of 90 minutes were arranged over a period of five weeks. During the sessions, each of the 45 photos he had taken during that time was discussed with Nick. The author asked 'Tell me about this photograph?' and any

comments and information he gave were recorded with the relevant photograph. In the final session Nick put all his photographs into an album and his comments were written next to each. Themes from the photographs were discussed and a reflective account was written after each session. The author carried out further thematic analysis, the content of which was discussed with Nick for agreement.

Results

Charles

Charles sang a combination of familiar songs and his own improvisations, ultimately recording 23 songs. He often provided a spoken introduction and used complex 'guitar solos' throughout. He expressed many different emotions through his work and particularly enjoyed listening to the recordings. A thematic map showing the three main themes in Charles' work is presented in Figure 1. The subject matter in Charles' work can be constructed into three main themes; 'Music', 'Travel/Transport' and 'Strong Emotions' all linked by a sub-theme 'Memories/Nostalgia'. Remembering is a very important part of his work, whether it is places he has visited, events that have happened, or television and music from the 1970's and 80's. However his work goes beyond reminiscence, demonstrating reflection and resolution, as can be seen in the three main themes.

Music: Throughout Charles' work there are many references to himself as a music maker and this theme is strongly linked to the sub-theme 'Competence', both themes often occur in close proximity to one another e.g. lines 708-710 "Oh we couldn't manage without you Charlie, you're the only one that can sing". Within his area of competence, music and song, Charles appears empowered and demonstrates an ability to express himself which eludes him when speaking. An example of this is a song he sings about a bad experience with a bus driver. In the spoken introduction he appears demoralised and sad; however he follows this with over a minute of loud 'air guitar' solo and lyrics firmly locating the problem with the driver. Charles ends the song with the rousing protest "Keep your opinions to yourself". Other examples of his ability to protest using song also occur in his work e.g. "I don't want anyone coming and telling me what to play" and "And no more teasing now", and give insight into some of the attitudes he has to contend with as an adult male labelled with a learning disability.

Travel/Transport: There are many examples of journeys, travel and transport in Charles' work and there is a strong sense of movement throughout. This theme is also linked to the sub-theme 'Competence' revealing an identity of someone who has 'been places'

physically on aeroplanes, boats and trains, but also someone who has made emotional journeys, for example coming to terms with the death of his father or leaving home.

Strong Emotions: Charles freely expresses the strong emotions he clearly experiences in his music, particularly engaging with themes of ‘Love and Longing’, and ‘Loss and Redemption’. The first of these sub-themes occurs frequently and is usually expressed in songs and lyrics he already knows. With regard to ‘Loss/ Redemption’, he sings about loss and brokenness on 13 occasions and on 11 of these the theme is followed by resolution. Two contrasting examples of this are a poignant song about the loss of his father, with subject matter relevant to anyone who has experienced grief, and an amusing song about breaking and replacing his wardrobe, in which he addresses the embarrassment of being the cause of this event.

The thematic analysis of Charles’ work reveals a multifaceted personality: someone who can be funny, poignant, wise, reflective, empowered and very entertaining. Asked what he thought of his work, Charles replied “It’s lovely, there’s more to it than meets the eye”. It also appears that Charles can use music to improve his mood and at the end of the first session he commented “I feel happy now”.

Anne

Anne recorded 43 songs and the majority of these were her own improvisations. She asked to listen to each song after it was recorded and was pleased with her work. Many (39) songs were dedicated to individual members of her family, friends, work colleagues or pets. A thematic map of the main themes in Anne’s work is presented in Figure 2. The subject matter in Anne’s songs can be categorised into two main themes; ‘Appreciation’ and ‘Maintaining Relationships’. These themes are situated within the form of a litany, a long list or catalogue. On one hundred and thirty seven occasions Anne tells someone she loves them and on fifty two occasions that they are amazing.

Appreciation: The songs about Anne’s family, friends, work colleagues and pets are full of appreciation for what they do for her, particularly the positive way they make her feel about herself, and the qualities she values in them. For example, “And he’s very very funny, and he takes me jogging” (lines 87,88). Other examples of this include her appreciation of someone decorating her room (lines 33,34), inviting her to watch a programme (line 94), washing her hair (line 201) and taking her for a nice meal (line 420). Anne specifically names the qualities she appreciates about the person the song is dedicated to in her work; the qualities nice, kind, funny and beautiful are commonly included. The qualities she values cross many common social boundaries, such as age, race, status, intelligence and wealth.

Maintaining Relationships: There are many references throughout Anne's songs to the importance of maintaining relationships, for example, "And she's my best friend, When we met we've been friends a long time" (lines 17,18). She demonstrates a clear understanding of how to achieve these e.g. sharing interests, keeping in touch/in mind and inclusion. She often refers to the interests she shares with others (e.g. watching television, listening to music, jogging, clubbing, holidays and dancing) and choosing to share others' interests with them. She also mentions the importance of keeping in touch, for example "I talk to him on facebook" (line 64).

Anne had a clear purpose in her work, to include all the people who were important to her, and she was anxious about forgetting someone or leaving someone out. She demonstrates particular maturity towards people joining her family, such as step-parents and in-laws, revealing an understanding of their need to feel included and a genuine appreciation for these relationships in her life. The thematic analysis of Anne's work provides much information about her interests and the depth of appreciation for her relationships. It also gives insight into some of her values and particular gifts; an appreciation of, and sensitivity to, what are often overlooked qualities in others and an ability to maintain diverse relationships.

Becky

Becky created a scrap book of work which included various pictures chosen from magazines, many small pieces of coloured and holographic paper, punched paper shapes, photographs and drawings. The reason she chose a particular image was written next to the relevant picture in her scrap book. The main themes in Becky's work are presented as a thematic map in Figure 3. The two main themes which emerged 'Comfort' and 'Attention to Detail' were constructed from the work Becky produced and reflections on the process.

Comfort: A great number of the images that Becky selected from magazines featured food, soft toys, animals and babies, and she associated almost all of these images with another person e.g. "This is what Andrew would like". This suggests an interest in comforting objects both for herself and for others. It demonstrates that Becky notices the objects which her friends value and her desire to establish common interests with the people around her.

Attention to Detail: Becky was very methodical in the way in which she produced her work, using small punches and scissors to cut paper into many tiny pieces, all of which she stored safely in envelopes and folders. This attention to detail is also apparent in her references to appearance. In her scrap book, most of the pictures which are not of food, soft toys or animals are of women, and all of Becky's comments refer to their appearance,

expression, or what they are holding. For example, “She’s got glasses” (page 21) or “She’s drinking a cup of tea” (page 25). This provides a valuable insight into Becky’s reliance on women for personal care.

An important expression of Becky’s attention to detail can be found in the sub-theme ‘Discarded/Valued’ and was demonstrated when she used the shaped punches; she was extremely reluctant to dispose of card that the shape was punched from and it was of considerable value to her. This may give some insight into why she continually carries a bag filled with paper (e.g. envelopes, raffle tickets and flyers) which others would discard. She values what others see as waste and wishes to keep it safe. During the sessions Becky was careful not to miss or lose any tiny bits of paper, noticing any that escaped. This ability to notice what may be discarded, lost or marginalised extends to other areas of Becky’s life. It is also evident in her scrap book, where she includes people from her community who could be at risk of marginalisation. Therefore, the thematic analysis of Becky’s work gives insight into some of her immediate concerns and also highlights important skills and abilities; the ability to notice and value things others do not, and inclusion of those on the margins of a group.

Nick

Nick shared 45 photographs during the project and time was spent discussing the photographs together, leading to an understanding of the meaning he attached to each photograph. The photographs fall into three categories; ‘People’, ‘Celebrations and Meals’, and his own ‘Possessions and Interests’. These three themes all contain elements of an overarching theme which Nick appears to explore in his work, that of ‘Hidden’. A thematic map of the main themes is presented in Figure 4.

People: Many (22) photographs featured people, typically at close range. From his reaction to each picture, Nick clearly knew every person photographed, but often struggled to remember their name. These photographs demonstrate how important his friends, family and supporters are to him. It also indicates that he has developed a strategy (using his camera) to overcome memory difficulties. Specifically, he can convey that he remembers someone even if he can’t recall their name.

Celebrations/Meals: Nine of the photographs were of celebrations or meal times, times when people gather together. These are popular times for photographs to be taken and Nick shares this interest with many other people.

Possessions and Interests: Fourteen of Nick’s photographs were of himself, his possessions or his interests, and looking at and discussing these gave him much pleasure.

This group of photographs provide a valuable insight into the subjects which capture Nick's interest and how he likes to spend his time, which may inform interactions with Nick.

Hidden: Discussions with Nick revealed that the focus of the picture was hidden or obscured. Some examples of this include; a photograph of a computer which Nick describes as a photo of 'Thomas', and on closer scrutiny 'Thomas the Tank Engine' can be seen on the screen and a photograph he describes as 'My Cup' where the cup is placed directly in front of a kettle and can barely be seen. There is a strong theme across all Nick's work of looking beyond the surface and revealing what may be hidden.

Therefore, by creating a piece of work based on individual skills and interests, those labelled with a learning disability were able to communicate about their lives on a number of different levels. The work produced conveyed many of their day to day concerns and preferences, but also gave insight into their personal lives, qualities and values.

Discussion

The results of this study support the position that Life Story methodology combined with the use of creative arts can be an effective means for people labelled with a learning disability to communicate about their lives (O'Shea 2009). The inclusive and participatory nature of the methodology, and the creative approach used, enabled those taking part in the current project to contribute on their own terms, as well as being an enjoyable and rewarding experience, it provided a rich picture of each person's life, skills and concerns. The participatory approach used, therefore, would appear to be a successful means of empowering individuals and enabling their voices to be heard. The individuals who collaborated in the project chose to work with different creative media and the results confirm that the three media chosen each provided useful means to negotiate communication differences and share life stories. The use of collage and photography were particularly effective media for those with limited verbal ability to communicate their interests and concerns.

The importance of this communication should not be underestimated. Lack of knowledge of an individual was identified by a recent report as one factor contributing to the deaths of people with learning disabilities (CIPOLD, 2013). The enquiry concluded that having a clear understanding of each person with a learning disability as an individual with a unique life history, is an important aspect of responding appropriately and effectively to continuing health needs. In particular, the report acknowledged the role of support workers and stated that their understanding and appreciation of the person they support could make a substantial difference to health outcomes. At present, there are often substantial differences between the communication skills adopted by carers and the comprehension of the person for

whom they are caring (Bartlett, 1997). The current study suggests that a range of communication types may be used to enhance communication and this may be particularly important for issues such as the identification of distress and end of life care where such communication difficulties are particularly apparent (Regnard, et al. 2003).

A recent report from the Royal College of Speech and Language Therapists (RCSLT, 2013) also emphasises the importance of good communication in the lives of those with a learning disability. The report identifies five good communication standards which provide a framework to assess whether good practice is being implemented in services. It also suggests that providers need to access and use a wide range of tools, techniques and technologies to support communication. From the results of the current study, it would appear that creative Life Story methodology could provide one such tool to enable best practice, in particular supporting Standards 3), *Staff value and competently use the best approaches to communication with each individual they support*, and 4) *Services create opportunities, relationships and environments that make individuals want to communicate*.

In a National Centre for Research Methods Review Paper, Nind (2008) states that people with learning / communication difficulties have important perspectives and experiences to contribute and Boxall (2010) similarly comments that those researching disability have a responsibility to develop creative, innovative approaches which include people with profound and multiple learning disabilities. The rich information expressed in this study suggests that the use of creative Life Story work could also provide an important means of involving people labelled with a learning disability in qualitative research. One of the challenges researchers may encounter is how to address the inevitable power imbalance presented when working with a devalued group of people. Cooke and Kothari (2001) suggest that participatory approaches can act to retain researchers control whilst presenting them as benign arbiters of neutral or benevolent processes. In relation to this criticism, the author has aimed to remain critical and reflexive throughout this study, but the impossibility of eliminating the power imbalance should be acknowledged. Nevertheless, participatory Life Story work using creative methodologies would appear to address some of the challenges and could provide the means for individuals with more profound needs to 'have a voice' and influence research / practice issues.

Boxall (2010) suggests that in addition to uncovering the perspectives and experiences of people labelled with a learning disability, creative and innovative approaches to including individuals in research may serve to engage support staff and enable them to develop different and less deficit-based understandings of the people with whom they work.

She quotes a care worker's response to research using photography ("It's a key into some people where you wouldn't necessarily have a way in") and advises that the engagement of the staff in the research and their renewed interest in residents' communication was evident in the post-project interview. This resonates with the findings of Hughes (2011) in her follow up study to the Life Story work carried out by the NIID. The engagement of support staff was evident in the current study; the process, and pieces of work produced, have opened up conversations and have enabled an appreciation of each individual's gifts and skills. Nick, Charles and Anne have presented their work to a group of about forty supporters and friends, where their voices, and in Nick's case his life perspective, could quite literally be heard or seen in the extracts of work they chose to share. The response was extremely positive.

To conclude, the four people who participated in the study shared generously about their concerns and their lives. Their work revealed valuable information about their beliefs, experiences and values. This demonstrates the importance of finding creative ways to negotiate communication differences, including people labelled with a learning disability in research and developing a less deficit-based understanding of learning disability. If this can be achieved, the outcomes may help to challenge attitudes which undervalue or devalue the lives of those labelled with a learning disability and may contribute valuable perspectives not otherwise easily accessed.

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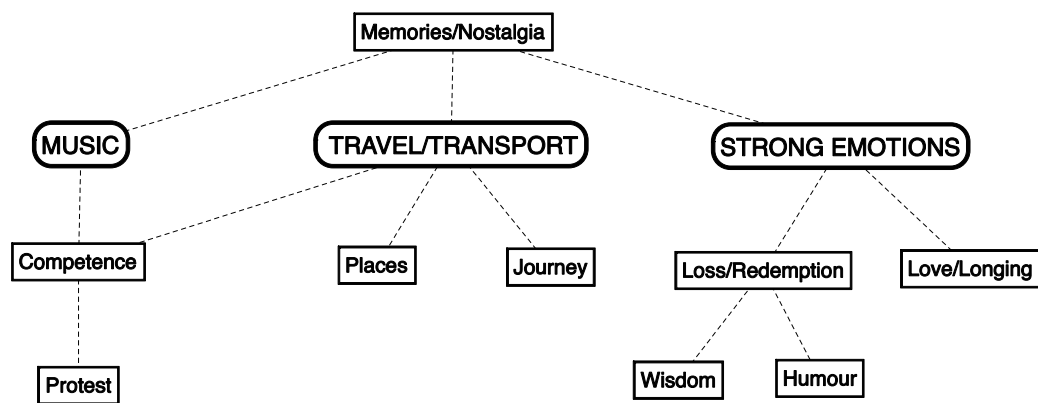


Figure 1. Thematic Map Illustrating the Main Themes Identified in Charles' Work

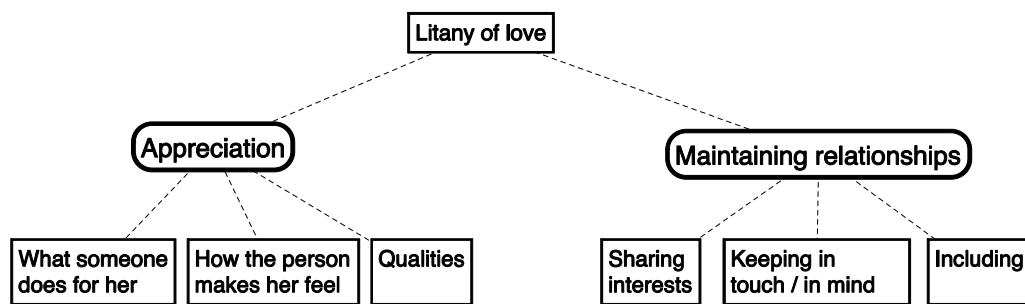


Figure 2. Thematic Map Illustrating the Main Themes Identified in Annes' Work

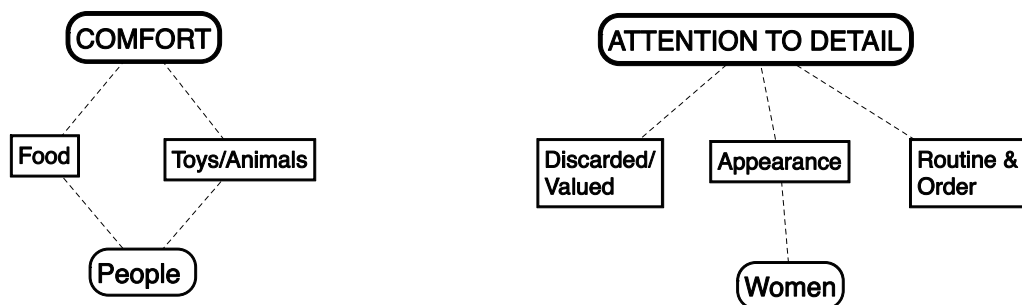


Figure 3. Thematic Map Illustrating the Main Themes Identified in Becky's Work

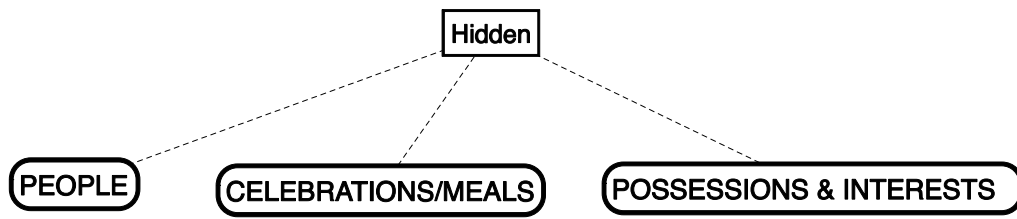


Figure 4. Thematic Map Illustrating the Main Themes Identified in Nick's Work